

Testimony of Desiree Mead to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*

February 6, 2009

Senator Harris, Representative Ritter, members of the Public Health Committee: Thank you for giving me the opportunity to speak to you today about *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*. Until January of 2008, Cystic Fibrosis was a term I had heard in passing and a few times read about, but only because it was in medical or nutritional literature I was perusing. It had no impact on my life directly or indirectly through friends or family. In short there was no reason, in my mind, for me to be concerned that my newborn should be tested for it. We had many reasons not to consider this screening. My family had been through financial difficulty, beginning in October of 2007 with my husband looking for work after college. My insurance plan makes me pay for 80% of hospital stays, lab testing, and diagnostics. Neither of our families had any history of C F, or was more than remotely aware of its existence.

It was only the feeling I had during pregnancy that this child was so much different than my other. Some silly notion I had that since the pregnancy was so different, the child would be, too. Really no more than a whisper of superstition, or maybe it was intuition as it turns out, that made me read the paper in my postpartum room and think, "Why not, what could it hurt." I had every shot and test they offered done so I could ease my mind that she was a perfectly healthy, normal child.

My mind let all worries go the very minute it was out of my hands. I was so glad for the beautiful gift I held in my arms, and every thing was going much better than I planned. She slept through the night from day 1, breast fed readily at even intervals, slept like clockwork during the day.

My life was perfect and I started to drive my older child to after school activities after 1 week home. Arriving at the first activity, my phone rang. I sent my child into class, and answered my pediatrician's call from his home phone number as a chill ran up and down my spine. Doctors don't call from home unless you call them. Something was wrong.

I don't remember the exact words he used, I was scared numb. The baby tested positive for Cystic Fibrosis on a genetics test. Something about 2 strands of recessive gene detected, yes it was definitive, no it could not be a mistake. He wanted to let me know as soon as possible, since, with early treatment people are surviving into middle age. Middle Age!

Devastation does not begin to describe the feeling I had to sit through class with. All I could do is stare at my perfect little baby and wonder, "Where is the broken part hiding? Why didn't he tell me how to fix it? What if I didn't find out now? What if she had gotten sick first?"

Statistics mean nothing when it is your life in the balance. Would you rather be mostly sure that your child's first cold would not impair lung function for life? Pretty sure that your child is absorbing nutrients necessary for growth and development? I knew from 1 week, and we still ended up having a short hospital stay at 9 months old. She had been on a special diet and supplement regiment since 2 weeks old and she was a strong active baby.

We were admitted the day after she took her first steps. The doctors knew exactly what to look for and what we were dealing with, so she fully recovered. Had we not known, her nutrition would not have sustained her immune system and her growth and development. Had we not known, that could have been her last cold. The only reason we are informed now, is because I elected, on that fateful day of her birth, for the testing.

It would have been just as easy, so easy, to check the next box over, and be heartbroken with a very sick toddler today. Instead, I am learning strategies every day to make her life happy, healthy, and normal and keep her going at the breakneck pace she is developing at.

Again, I thank you for your time and consideration on this critical screening bill.

Sincerely,
Desiree Mead, CPhT